Count Me In!

Count Me In Conference

January 25 to January 27, 2001

Conference Report

NWT Council
for Disabled Persons

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January 25-27, 2001

Yellowknife
Northwest Territories

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Our Purpose

In November 2000, a comprehensive needs assessment of persons with disabilities in the Northwest Territories called, *Living with Disability... Living with Dignity*, was released. The report described the nature of living with a disability in the NWT, the services currently used and those programs and services which are needed.

The needs assessment heard from 807 persons with disabilities, one-third of the people in the NWT with moderate to severe disabilities. The voices of more than 200 caregivers were also heard.

The purpose of the Count Me In Conference was to provide an opportunity for discussion of the research results among persons with disabilities and caregivers from across the NWT. Delegates were also invited to contribute to an action plan to address the needs of people with disabilities and their families.

The conference was the largest disability gathering ever held in the NWT and an important opportunity for people affected by disability to meet and network with each other.

Living with Disability... Living with Dignity was produced through a government/ non-government partnership consisting of: Yellowknife Association for Community Living,

GNWT Department of Health and Social Services, YWCA of Yellowknife, GNWT Department of Education, Culture and Employment (Culture and Career Division), Human Resources Development Canada, NWT Council for Disabled Persons, and self-advocate MaryAnne Duchesne.

These partners supported the NWT Council for Disabled Persons in applying for funding from Human Resources Development Canada to hold this territorial conference. The Council is grateful for that funding and the support of the Social Policy Development staff of HRDC in Ottawa. As well, we are grateful to the Department of Indian and Northern Affairs in Yellowknife which contributed the cost of travel for up to five of the approximately 70 community delegates. The GNWT Department of Municipal and Community Affairs contributed to the travel costs of two of the Council's board members and the NWT Development Corporation contributed a gift to one of the conference speakers.

Planning for the Count Me In conference involved a committee of people, most of whom are associated with agencies providing services and programs to persons with disabilities and their families. With the support and guidance of this planning committee, the NWT Council for Disabled Persons hired a conference planner, and additional temporary staff, to bring together delegates from across the NWT. Many volunteers were involved as facilitators, notetakers and in other capacities. Guest speakers and exhibitors brought the total number of people involved in the conference to close to 200.

The conference had three themes – Income, Education and Disability Supports. These themes were prominent in the needs assessment results and were highlighted during an informal survey of persons with disabilities and family members during the summer of 2000. These themes are also consistent with those included in the joint federal, provincial and territorial policy vision, *In Unison: A Canadian Approach to Disability Issues*. This vision recognizes how important it is for governments to engage the disability community in working toward the goal of full citizenship and inclusion for Canadians with disabilities.

Conference Participants

Conference delegates came from 22 NWT communities. In addition, there were delegates or guest speakers from Quebec, Ontario, Saskatchewan and Alberta.

Most delegates were either persons with disabilities or caregivers, representing a cross-section of ages, disabilities and life circumstances. A number of territorial and federal officials participated in the conference as delegates, presenters, exhibitors, notetakers or facilitators along with representatives from non-governmental agencies.

The keynote speaker was comedian and motivational speaker, Gord Paynter, from Brantford, Ontario. The conference co-chairs were self-advocate, MaryAnne Duchesne, and Sue Heron-Herbert, executive director of the NWT Native Women's Association.

Guest speakers included the Federal Member of Parliament for the Western Arctic and Secretary

"I learned that I'm not a loner out there. There are many more with the same solutions, problems, and ideas."

of State for Children and Youth, Ethel Blondin-Andrew, GNWT Minister of Education, Culture and Employment, Jake Ootes, and Minister of Health and Social Services, Jane Groenewegen. Lucie Lemieux Brassard, of Montreal, spoke about self-advocacy and Kyle Prettyshield, of the National Aboriginal Clearing Connecting House on Disability Issues, spoke about aboriginal disability issues. Other speakers and panellists are listed within the agenda in Appendix A.

One of the goals of the conference organizers was to ensure that accommodations were in place so that anyone with a disability could participate in the conference if they wanted to. A separate report was prepared by the NWT Council for Disabled Persons on accessibility measures for the conference to provide information for planning future conferences.

Conference Agenda

The Count Me In Conference was planned to maximize the comfort level of participants, encourage sharing and allow for a substantial exchange of information. Small group discussions, guest speakers and panels focused on the areas of income support, education and personal services and supports.

Guest speakers and/or panels began each session with information about the area being

considered. Then, delegates had the opportunity to describe their experience in each area and recommend changes which would improve their quality of life. Each small group had about ten participants, as well as a facilitator and a scribe.

The notes from each small group were collected and put together into a three-page summary which each delegate received on the last day of the conference. Delegates had an opportunity to review the summary and add any additional remarks. The summaries were presented by three delegates, Doreen Baptiste, Edna Elias and Steve Peterson. The summaries are included in Appendix B. A detailed account of small group sessions is included in this report. The plenary and small group discussions are summarized to present priorities for action.

On the closing morning of the conference, the delegates also had an opportunity to send correspondence regarding their situation to the Premier of the Government of the Northwest Territories. Participants were aided in this activity by the scribes, facilitators and elected officials who were present. The MLAs in attendance gave delegates advice on how to effectively lobby and advocate for the changes they want.

Talking circles were also held on the last morning to help delegates summarize their feelings and plans with each other before heading home. A delegate at each table was chosen to be responsible for keeping the group's 'talking stone' until they could return to the next gathering.

"The people in my town really need educating about this. They just don't know."

Count Me In Conference Summary: Priorities for Action

The priorities for action identified and discussed by conference delegates are summarized below.

1. Better information and better access to information for persons with disabilities and their caregivers.
   - About income support programs, educational and employment options, and personal services.
   - A toll-free 1-800 number and Web site for persons with disabilities are recommended along with a regular territorial newsletter with updated information.
2. Development of policies and legislation to mandate services for persons with disabilities and identify who is ultimately responsible, accountable and has authority for persons with disabilities and their families.
   - There could be an Ombudsperson, a Ministerial Advisory Council for Persons with Disabilities, and/or a Minister Responsible for Persons with Disabilities, along with a national and territorial Bill of Rights for Persons with Disabilities.
3. Better public awareness of the challenges faced by persons with disabilities as well as the many contributions persons with disabilities can, and do, make to society.
4. Territorial conferences and regional conferences for people impacted by disability on a yearly or biannual basis.

Income

5. Higher income levels for persons with disabilities to live with dignity.
   - Federal and territorial income programs which keep up with the cost of living, the rising costs of food, fuel and other goods and services, and the higher costs of living in the North.
   - Gifts, inheritances and seasonal income from other family members which do not affect financial assistance.
6. The removal of disincentives to employment.
   - Higher levels of income without penalty or 'clawing back' of financial assistance.
   - A transition from income support to employment longer than three months.
7. Persons with disabilities accessing financial assistance be treated with respect.
   - Financial service providers trained and sensitive to the challenges and circumstances that persons with disabilities and their families live with.
   - Medical personnel involved, along with income support staff, in decisions regarding the financial support of a person with a disability.

Education

8. Education and training which support children and adults with disabilities to reach their full potential.
   - More training for parents, teachers, adult educators, special needs teachers and classroom assistants about disabilities and strategies to help people learn.
   - Government funding which supports special education consultants, special education resource teams and special education teachers.

"You don't need an advanced education to be successful."

- All students with disabilities, both children and adults having access to individualized, coordinated learning plans that focus on their strengths and abilities.
- Promotion and funding of options such as home-schooling, distance education, literacy programs, adult upgrading, early intervention programs, retraining programs and alternate schools.

Disability Supports

9. Greater access to a wider range of assessment, diagnostic and remedial services, equipment and other supports.
   - Making the early diagnosis and assessment of children with disabilities a top priority.
   - Developing a specialty team (with an Occupational Therapist, Physiotherapist, Speech Pathologist and Psychologist) to provide regular and appropriate services to each community.
   - Increased funding to persons with disabilities for special aids, appliances and equipment, transportation, home renovations, learning aids, medical necessities, respite care, ambulance costs, child care, dental care, eyeglasses, and hearing aids.
   - Paraprofessional home care and respite care personnel trained in each community. Youth and Community Health Representatives can be trained to provide these, and other services.
   - Disability supports and services which are available throughout a person's life, wherever they live in the NWT and which are not tied to education, employment or other activities.

Detailed Results of Small Group Sessions

Session One: Money and Dignity

The small groups were asked to discuss the following question:

What kind of system could meet the basic needs of people with disabilities, provide dignity, and at the same time encourage employment where possible?

Problems: Money and Dignity

- participants expressed real frustration with the amount of money they are forced to live on
- it does not cover even the basics of life
- many people are forced to rely on family members and friends to survive
- present levels of income support endanger safety and exclude many people who need assistance due to a disability

"Being disabled means living in poverty."

- income support for persons with disabilities, through Human Resource Development Canada, is $6,000 a year
- some delegates get rental ceilings of only $400 a month when all apartments in their town are at least $600 to $700 a month

- these amounts are based on a chart and are not flexible to the individual needs of each person
- in the experience of most delegates, there was no additional help from local Social Services offices
- with no personal needs taken into account, many persons with disabilities found they could not afford the transportation to appointments and therapy sessions
  - very few communities have handi vans
  - benefits are not tied to the cost of living, nor do they take into account seasonal problems such as ferry and road closures
  - benefits do not allow for the higher costs of living in small communities
  - special equipment is not covered by anyone
  - hearing aids are very expensive ($2000 each) and only $500 is covered

"This system prevents people from getting ahead rather than assisting them."

- there is frustration over the income support regulation that does not allow recipients to make extra money to supplement their income support cheque
- earnings from other family members are also deducted from income support payments meaning that there is no way to either 'get ahead' or maintain an income that meets basic needs

"There is always rules above rules above rules."

- participants expressed real frustration over the existence of various confusing income support systems; the rules and regulations of each system are confusing
- many were unaware of the CPP disability plan and confused about the requirements of the income support system through HRDC
- there is limited awareness within the disability community about extended health benefits and how to access alternate therapies
- persons with disabilities in small communities have an even harder time accessing both information and income support programs

"People tend to want to push disabled people into a group like they have a disease."

- many delegates expressed frustration that income support programs and Social Services fail to consider their personal situation. They are just all fitted onto one chart no matter what their situation
- necessary home renovations, respite care, transportation, winter clothing needs, hearing aids (for both ears) were not considered in making an overall income support assessment
- income support programs do not appear to recognize that some disabilities are permanent

"Being disabled means living in poverty."

- many skills such as banking, budgeting, independent living, life skills and self-advocacy are not taught to people with disabilities

- there is no long-term funding available for children who may reach the age of majority but are not capable of supporting themselves: after 19 years of age these children (both in foster care and at home) are not supported in any way
- delegates wondered what kind of support is available to children with FAS and FAE who cannot participate in school past grade 8 or 9
- several parents expressed frustration and anger that they felt forced to institutionalize their children in order to get any help from Social Services

"They don't want to help you. They want you to make a 'productive choice'."

- the rules of the education system do not match available income support funding nor do they take into account the unemployment situation

"I feel like an outcast."

- many delegates feel that the public doesn't adequately understand what they are forced to live on

Solutions:
Money and Dignity

"Who decides what the basic needs are for a person with disabilities?"

- delegates want the right to determine for themselves what their "basic needs" might be
- delegates agree that there must be higher income support levels for people with disabilities, and money for special equipment, transportation and renovations
- people need more information about all the income support programs available

"A new program should be created separate from Income Support and similar to pensions for seniors."

- people with disabilities should have their own separate pension plan like seniors
- this plan needs to take into account the personal situation of each disabled person in terms of: home renovations; respite care for caregivers; home care; clothing allowances; education, with the necessary adaptive equipment; personal needs; ambulance costs; training for caregivers; child care; medicine; aids, appliances and equipment; dental and eyeglasses; phone; recreation; furniture; fuel subsidy; food increases twice yearly due to ferry; allowances for food allergies; bimonthly rather than monthly payments
- persons on CPP pensions should be able to access subsidies as this plan does not come close to covering the cost of living in the North

- pensions should allow a certain level of income from employment and not immediately be cut off if the person begins some level of employment
- programs such as the assured income program in Alberta and the programs in Ontario and BC are possibilities (they allow baseline amounts with minimums for housing and are related to family size)

- there needs to be easier methods of accessing income through direct deposits to accounts
- delegates wondered why there is not a committee which assesses needs accurately and re-evaluates them on an ongoing basis... why do we have to fit onto a chart?

"When they learned my son had a paper route they took that money off my cheque."

- delegates want to see the disincentives to working removed, i.e. the 'clawback' of monies from their income support cheques if money is earned
- gifts and inheritances should not be deducted from the amount they receive
- child tax benefit and GST rebates should not affect either CPP or income support
- income from seasonal work such as fishing should not be deducted from the income support cheque

- income from children should not be deducted from income support given to people with disabilities
- income support for disabled parents with dependent children should take into account the needs of the dependent children
- the tax credit system needs to be improved to better reflect the financial situation of persons with disabilities
- there needs to be provisions for the financial support of children over 19 who no longer qualify under the child welfare system
- funds should be available for people who want to go home for special occasions or have their family visit them
- there needs to be financial help for parents of disabled children even if they are not in care

"We need more workplace awareness of disabilities and we should subsidize employment suitable to persons with disabilities."

- delegates felt frustrated that employment was seen by all service providers as the only viable goal for persons with disabilities
- those who can work should be allowed to work to the level of their ability
- the period of transition from income support to employment should be longer than three months... it should be a year
- there should be subsidized employment for persons with disabilities
- it should be possible to run a home business from public housing

"We really need an Ombudsperson, a toll-free number, a central location and an Advisory Committee to improve this situation."

"I have to involve my MLA to get anything done."

- delegates felt their situation would be greatly improved by the presence of an Ombudsperson empowered to advocate for persons with disabilities
- along these lines, delegates asked that a toll-free line be established for persons needing information and assistance with advocacy... they need a centralized place to access information and services
- delegates think the public needs to know about their situation so they will be better supported in their attempts to solve the income support problems for persons with disabilities
- a number of ideas were generated around this idea: advertising (in aboriginal languages), Web sites, sending representatives from the persons with disabilities community to speak with politicians; the creation of a statistical picture of persons with disabilities; petitions; and, the utilization of service clubs who assist the disabled
- delegates asked that a Ministerial Advisory Council for Persons with Disabilities be established with the aim of improving policy and legislation in relation to disabled persons

"We need front line workers with compassion, not people who act like cashiers who say they are 'catering to people with disabilities'."

- delegates referred to being treated disrespectfully by income support personnel
- they would like to see income support programs for persons with disabilities staffed by persons with disabilities and they would like to see all income support workers receive training in the area of human relations, conflict resolution and respect
- they feel that workers in the system need to show more support and encouragement to clients with disabilities
- in that regard, delegates wondered why decisions about their situation are made by office people rather than by medical people who would understand their situation more completely
- they wondered why there were not people available for counselling either, as they often feel the need for personal psychological support
- some delegates wondered if it might be better to transfer income support, at least for persons with disabilities, back to Social Services
- delegates questioned why existing programs and government departments can't work more closely together to address the needs of persons with disabilities

"As soon as they look at you and see you are disabled they say you cannot work... even when I have the qualifications as a teacher."

- delegates wondered why more people with disabilities were not being hired in government offices in general
- they pointed out that many persons with disabilities have the capacity to make a big contribution to the public, using the example that hearing impaired people just need the right equipment to work productively

Session Two: Lifelong Learning

In this small group session, participants were asked to address the following question:

How can children and adults with disabilities get the support they need to reach their potential within the NWT education system?

Problem Areas for Children: Lifelong Learning

"I know a student who was labelled 'low-average' when in fact he has a learning disability."

- delegates report that there are not enough specialized programs and special needs teachers to meet the needs of the number of children with disabilities
- they believe that southern institutions often provide better programming to these children as northern teacher's aides are not fully trained to deal with all disabilities
- as a result, many parents feel that their children are not being educated, simply "managed"
- it is very hard to get appointments and assessments of children with disabilities

- teachers are unaware of the child's situation and their records are simply passed from grade to grade
- these problems are compounded by misdiagnosis
- delegates believe that education levels in the NWT are lower than what school boards and teachers say, with the result that there is no proper consultation between schools, parents and teachers

"When dealing with a child with a disability it is always a fight... and it doesn't need to be."

- there is limited understanding of children with learning disabilities, Down Syndrome and autism
- there is little accommodation of children with intellectual disabilities
- parents and foster parents don't get enough, if any, information about their child's condition and are left on their own to try and find services and programs

"Back in 1997, my child was assessed with FAE and the doctor called and told me this and then nothing else was done."

- Health and Social Services and Education often push children back and forth between them, with neither one ever taking responsibility for the child's education, and other developmental needs
- speech pathology and occupational therapy appointments are just 15 minutes each and parents, who are unsure of what they are doing, are given all the responsibility to follow up
- in regard to working with various levels of government, delegates expressed disappointment that ECE did not consult with parents in their recent study about student needs

Problem Areas for Adults: Lifelong Learning

"Ask me, I am the consultant, I am the one who knows what's best for me."

- adults with disabilities face many of the same challenges as children in terms of accessing suitable education
- delegates feel that there are not enough adult literacy and basic education classes available, particularly in communities

- along with this, there are not enough retraining programs for those who become disabled later in life... training programs that limit funded participation to six months are not adequate
- in addition, there is for adults, like children, very limited access to ongoing assessment

"Too much emphasis is placed on cost or perceived cost."

- land claim organizations refuse to fund programs or services that they think government should pay for
- governments won't cover them either so the service is not there... this has been most noticeable in the area of funding special needs equipment

Solutions for Children: Lifelong Learning

"There is no reason these services cannot be provided here. The NWT is not a third world country."

- suggestions in the area of childrens' education included: one-to-one training of parents and siblings so they can work with child with disability; tutoring by videotape; increased computerized learning

- parents would like to see their disabled children included in regular classrooms... if this is not possible, they would like to see individualized learning plans that accommodate different learning styles and abilities
- learning plans and educational goals have to focus on the child's abilities and be positive
- delegates worried that funding for special education teachers is left too much to the discretion of local school boards... they feel it should be a mandatory program available in all NWT schools available to everyone
- they also feel that all school boards should have special education consultants to oversee the training of staff and track each special needs child through the system from grade to grade

"The first five years are the most important in a child's life."

- parents would like to see pre-kindergarten programs that focus on early intervention and language development... more programs like Aboriginal HeadStart were suggested
- it was also suggested that special needs professionals be available to the daycare providers
- some delegates suggested that seniors be involved with the school system for early intervention services

- there should be Special Needs resource teams in schools
- other necessary services include: the full range of assessment (done both in the home and at school) and Occupational Therapists, Physiotherapists, Speech Pathologists, and Psychologists
- classroom assistants, all caregivers, teachers and school administrators need increased training around disabilities
- there was a call from delegates for more schools like the Learning Centre and Project Change which provide individualized learning to children with disabilities

"Simply removing children from any education system does not solve anything."

- there has to be recognition that not all children are going to gain a grade 12 education and alternate learning goals should be set by them and their caregivers and teachers

- all services have to work together and follow the child through all grades into adulthood; they need coordinated planning for everyone
- some delegates suggested that we should rethink the practice of 'social passing' as it doesn't really measure anything in the end

"Don't stop at the first sign of achievement. Keep up the program until the child doesn't need assistance... and knows it."

"A lot of families would keep their children at home if they had the support they need... financial, respite, home renovations."

- suggestions for supporting youth with disabilities included: a youth disability conference; basic life skills training (for all children and youth); summer courses; addictions awareness; cultural awareness training; art and hands-on industrial training; materials such as books with large print and braille; a role model program with adults with disabilities for children to emulate; work experience programs; sexuality awareness; homework clubs; tutoring; land skills programs; teaching of traditional occupations; cooking courses and money management.
- in addition, several small groups suggested the institution of a Junior Special Olympics in the NWT
- specialized regional schools for children with disabilities was another suggestion
- several delegates believed that school administrators need to have the power to enforce acceptable behaviour in schools and that there be mandatory involvement of parents in their child's education
- there needs to be some clarity around who is responsible for educating children with disabilities who are over 18

"Parents are the best advocates for their children."

- parents need training as well... they need to know more about how to help educate a child with disabilities
- they must find ways to work together to lobby for the programs their children need, and to learn from each other's success stories.
- parents have to use the resources that do exist efficiently and work for better services
- groups for parents whose children have specific needs like autism are an idea
- parents mentioned how hard it was to trust the care of one's child to others as there has been so much abuse of children throughout the territory
- home-schooling should be promoted as an option and parents given help to pursue this option
- in this vein, most delegates feel that communities have to be much more involved in their local schools, offering assistance and programs
- delegates hoped there would be better research in the area of educating children with disabilities

"When you give a child a choice you give them freedom."

Solutions for Adults:
Lifelong Learning

"Why not ask adults with disabilities where the money should go?"

- there were some creative suggestions from delegates in terms of providing more educational opportunities for adults with disabilities
- they wondered about having adult education classes within the existing schools (which might also assist with discipline)
- there were suggestions about making the existing college system more accessible with appropriate accommodation on site
- would it be possible for governments to release their employees to deliver literacy training to adults?

"I get frustrated trying to explain to the teacher that she has to look right at me when she's talking."

- adult educators need to know more about disabilities in general
- they need training in CPR, and criminal records checks for adult educators are essential

"As an adult learner I feel much older than the other students and I feel different and its difficult for me to speak out."

- adults need many of the same educational assistive services as children: assessments, speech therapy and coordinated case planning would help
- doctors, educators, home care and the family all need to work together rather than on their own

"I was just tired of doing nothing so I applied for adult education. Now I'm sitting in the classroom learning computers with a bunch of 20 years olds. I'm 57!"

- specialized courses for adults were recommended... they include: safety courses for pipeline workers; distance education courses by computer; job training and work placement courses
- some adults with disabilities also need adaptive remedial aids and special equipment
- funding for post-secondary training is necessary
- some adults with disabilities need transition programs to help them make the adjustment from high school to independent living... such a program should include life skills
- age shouldn't be a cut-off with programs like this
- one suggestion in this area was the establishment of 'halfway' homes where people can learn independent living skills

"I don't like being classified as disabled."

- some people mentioned that loans would also be helpful for starting businesses.

- delegates want to see more than what one person called "slave labour shops" as work opportunities... they want to see employment options that provide real employment value
- in addition, people need the chance to learn leisure activities and hobbies and take on recreation programs too
- people need to be shown how to do these things, not just told about them

Session Three: Personal Services and Supports

Delegates were asked to consider the following question in their small group session:

How can people in the NWT communities get the services and supports that they need?

Problems: Personal Services and Supports

"The number of disabled people is growing and increased home support is one of the answers... but we have a lack of trained people to do the job."

- delegates noted that services and supports are scattered, inconsistent and hard to access
- each level of government and land claims organizations say its not their responsibility to fund services and supports to persons with disabilities
- there are more services and programs in big towns and few in small communities... this means that families are often split up when a disabled family member is forced to leave town for services

- helpers that do come to town come only for short times
- there are few mental health professionals visiting the communities and we need resident services like PT, OT and Speech Pathologists

"I have to involve my MLA to get anything done."

- delegates believe that neither their communities nor the various levels of government understand the problems they face in accessing adequate and even basic services
- as mentioned in other small group sessions, a large area of concern was the lack of funding for home renovations and aids necessary in the home for basic functioning

Solutions:
Personal Services and Supports

"Communities can grow their own help with the right training and resources."

- delegates suggested the training of more paraprofessionals at the community level who could provide the home care and respite care needed by families of persons with disabilities
- the suggestion was made that Aurora College offer a course like this in the communities

"A lot of families would keep their children at home if they had the support they need... financial, respite, home renovations."

- they also suggested increasing the capacity of existing community home care teams so they could offer more local services
- can respite care be offered through the existing home care system?

- can home care be better connected to the medical community so there is a single point of entry for persons with disabilities?
- how does home care currently get referrals?
- delegates said they need more time with doctors and specialists... more than 15 minutes or even a half an hour visit
- can these professionals be used more efficiently?
- health professionals need to know what services are available so they can advise clients

"Our town (Fort Smith) takes accessibility seriously and we have won an award for it."

- in terms of municipal governments and band councils specifically, delegates wondered why they couldn't make buildings more accessible and provide services like handi vans
- delegates wondered why snow removal couldn't be a priority for these governments
- in this session, the issue of access to information came up again
- delegates made the following suggestions in this regard: more information about services in doctor's offices; a 'one-stop' shop or 1-800 number for information; information in MLAs

offices; a newsletter from the Council that could be sent both electronically and in hard copy to health centres, band offices, doctors, schools, mail boxes, etc.

- it was noted that services worked better in those communities that had inter-agency committees
- delegates asked that the premier and other government officials visit their communities more often so they know the issues related to persons with disabilities

"I don't like being referred to as "indigent" when I ask for a hearing aid. There are not many people who could afford one, let alone two."

- a number of suggestions were made that pertain to hearing disabilities specifically... teaching the public and especially service providers to speak clearly into message machines; providing information on hearing restoration options (like operations); teaching people how hearing can be damaged; providing the hearing impaired with amplified phones; telling people when you have a hearing disability

"We need to use existing resources better."

- some delegates wondered if community youth could be trained to work with disabled persons in their community
- several small groups suggested that Community Health Representatives (CHRs) could spend less time on administrative activities and translating, and more time assisting the disabled persons in their community and in the schools

- they wondered if the clerk/interpreters in the health centres couldn't take over the administrative duties of the CHRs
- there needs to be a lot more professional support in the communities from Occupational Therapists, Physiotherapists, Speech Pathologists, Psychologists and others
- local nurses are overworked and burned out and end up leaving just when they know the community people and their needs
- all community workers need more training so they can support each other
- could there be a specialty team that travelled to each community?
- the Stanton Hospital team is needed in Yellowknife so another team is needed to travel into smaller communities
- professionals and others need full client profiles when they are making decisions

"We need our own Bill of Rights for Persons with Disabilities. We need a Minister Responsible for Persons with Disabilities and a Ministerial Disability Advisory Council."

- delegates believe that services for persons with disabilities should be legislated and that a Bill of Rights for Persons with Disabilities is necessary
- they would like to see a Minister Responsible for Persons with Disabilities and a Disability Advisory Council that could work across departments and create a more cohesive web of services
- delegates want to see services taken out of Income Support and established, long-term, ongoing funding made available for all programs

- could there be a Disability Supports Program with ongoing long-term funding?
- can more money go to agencies to supply services?

"The people in my town really need educating about this. They just don't know."

- communities need to take more ownership of disability issues
- community meetings can create awareness of disability issues and encourage communities to take more responsibility for persons with disabilities within the community
- communities and regions could have their own conferences
- everyone needs to be included in all community activities and regular community activities that include persons with disabilities would be welcome
- would buddy systems work?
- delegates wondered if there was a home ownership plan for persons with disabilities

"You don't need an advanced education to be successful."

- other practical community suggestions included: a phone system where pushing one button brings emergency help: a central data bank. an affordable taxi system. a community list of people with disabilities and community advocates as resource people: a list of services available on diagnosis: a community United Way and Shriners Club
- community planning should include front line workers as well as decision-makers and government staff
- communities should build long-term facilities for the elderly and disabled persons with land claims funds

"I hope they hear us this time."

- government and all agencies and associations need to act on the results of the needs assessment study and this conference

Conference Exhibitors

GNWT, Municipal and Community Affairs

NWT Literacy Council

Human Resources Development Canada

Canadian National Institute for the Blind

National Aboriginal Clearing/Connecting House on Disability Issues

Canadian Hard of Hearing Association: Yellowknife Branch

Yellowknife School District #1, Bridges Program

Sledge Hockey of Canada

Yellowknife Association for Community Living: FAS Project

Active Living Alliance of Canadians with Disabilities

Special Olympics

Yellowknife Disabled Persons Work Strategy

NWT Council for Disabled Persons

GNWT, Health and Social Services

Learning Disabilities Association of the NWT

GNWT, Education, Culture and Employment

Conference Planning Committee

Bill Burles/Diane Cook/Aggie Brockman, NWT Council for Disabled Persons

Kate Tymstra, YWCA of Yellowknife

Lani Cooke/Miriam Wideman, Yellowknife Association for Community Living

Bernie Karpan, GNWT Department of Health and Social Services

George Glinka/Christina Vernon, Canadian National Institute for the Blind

Barb McDonald, Yellowknife Health and Social Services Board

Mike Mann, Canadian Mental Health Association

Barb Hood, NWT Seniors Society

Esther Braden, Canadian Hard of Hearing Association, Yellowknife Chapter

Jan White, Learning Disabilities Association of the NWT

Joan Hirons, Special Olympics

Margo Hopkins, Self-advocate

Rae Celotti, Yellowknife Disabled Persons Work Strategy

Judy McLinton, Promotion Committee

Greg Wurzer, Promotion Committee

MaryAnne Duchesne, Self-advocate

Darlene Mandeville, Prestige Planning, Conference Coordinator

Other Volunteers

Barb Hood
Bob Richardson
Cecily Hewitt
Don Babey
Doreen Cleary
Evelyn Blondin Forrest
George Glinka
Gillian Moir
Helen Ferrigan
Julia Flumerfelt
Kim Poulter
Lani Cooke
Lesia Lucan
Liz Parsons
Lucy Dillon
Lyda Fuller
Lyn Strickland
Marsha Argue
Nada Zadravec-Boote
Phyllis Sartor
Rodger Snow
Rosalind Foley
Roslind Minault
Roslyn Smith
Sarah Kelleher
Shari Driscoll
Sr. Nancy Wales
Sue Edmonds
Terry Garchinski
Val Braden
Wendy McPherson

Conference Evaluation

"I learned that I'm not a loner out there... There are many more with the same solutions, problems, and ideas."

Delegates were very pleased with the conference and highly energized by the experience. Every aspect of the conference was rated largely in the "good" to "excellent" category. Delegates were very appreciative of the high level of organization. They were grateful for all the personal services available to them in terms of transportation, finances, medical assistance, nutrition, accommodation and personal aids.

Comments on the evaluation forms focused on the conference as a very useful learning and networking experience. Many participants talked about 'having their eyes' opened about disabilities. A lot of participants also reported that they felt a greater sense of inclusion and much less isolated with their own personal disability concerns. In particular, participants noted the relief and satisfaction they felt when they met and spoke with others who have disabilities similar to their own.

The participants appreciated the speakers and their information, with a special note of thanks to Gord Paynter, the keynote speaker, who went a long way towards helping people relax and feel OK about their own situation.

It appears that the small group discussions were

generally the most popular activity at the conference. Participants felt that these groups gave them the opportunity to fully share their own stories, feelings and ideas with each other. The fact that participants were from all over the Territory, with some from southern Canada too, gave participants the sense that they are part of a large, active, committed group of activists who are not afraid to speak out for themselves.

The exhibits were also very popular as many people reported learning about services and programs of which they were previously unaware. In that regard, many participants asked that the next conference have exhibits and speakers in the area of alternative health and alternative medicine. There were also several requests for information, workshops and speakers, at future conferences, who can do some 'hands on' training and specialized workshops in the areas of advocacy, parenting, relationships, and caregiving.

At future conferences, delegates asked that more MLAs and aboriginal leaders be present to learn about their concerns and help design solutions. They also asked that more community people and youth with disabilities attend and speak out about their situation. Delegates especially want to hear from people who have developed creative solutions to their situation and have a positive, hopeful attitude towards their future.

The agendas of future conferences should also include an update from government

departments on the progress that has been made as a result of recommendations from this conference and the findings of the needs assessment done before the conference.

In general, participants would like speeches to be shorter, and they ask that speakers use more plain language. They would like more question and answer periods after each speaker.

Participants want to leave future conferences with a clear strategy in place so that progress on their issues, by government, agencies and themselves, can be checked from one year to the next. And, conference delegates would like to see regional conferences to enhance overall territorial awareness of disability issues. There were suggestions that the NWT Council for Disabled Persons expand into community development work and raise public awareness at that level about issues affecting disabled people. They wish the results of this conference to be publicly available.

At the close of the conference, 20 people filled out forms volunteering their time in the areas of board membership, advisory committee membership or peer support to a caregiver or person with a disability.

"This conference is a foot in the door for all disabled persons! Mahsi Cho!"

Appendix A: Conference Agenda

Count Me In Conference Agenda
January 25-27, 2001
Explorer Hotel, Yellowknife, NWT

Registration in main lobby of Explorer Hotel	Wednesday, 8:00-10:00 p.m.
Registration in lobby outside of Katimavik Rooms at Explorer Hotel	Thursday, 7:30-9:00 a.m.

Day One: Thursday, January 25

Continental Breakfast	8:00 a.m.
Opening Ceremonies Opening Prayer Welcoming Remarks: Bill Burles, NWT Council for Disabled Persons Conference Procedure Overview	8:30 a.m.
Keynote Speaker: Gord Paynter, Leave 'em Laffin'	9:00 a.m.
Health Break and Networking	10:00 a.m.
Plenary: Highlights of Living with Disability... Living with Dignity, the report of the NWT Needs Assessment of Persons with Disabilities. This report identifies the needs of people with disabilities and parents/caregivers in the NWT. Presenter: Lois Little, Lutra Associates Ltd.	10:30 a.m.
Conference Lunch: "Sharing Our Stories"	11:30 a.m.
Plenary: Advocacy and Action Guest speaker: Lucie Lemieux-Brassard, disability activist. A national context and personal perspective on the rights of persons with disabilities.	1:30 p.m.

	NWT Community Success Stories: Improving Access. Tammy Malgokak of Holman, and Sister Agnes Sutherland, of the Fort Smith Society for Disabled Persons, speak about making a difference by working together.
2:30 p.m.	Plenary: Show Me the Money – The Impacts of Income on Dignity Self-advocates Margo Hopkins and Vital Manual speak about the challenges of living on a limited income. Madeline Rabesca on a caregiver's perspective. An overview of the GNWT Income Support Program by Linda Ecklund of Education, Culture and Employment.
3:00 p.m.	Health Break and Networking
3:30 p.m.	Small Group Discussion: Addressing the Income Puzzle. What kind of system could meet the basic needs of people with disabilities, provide dignity, and at the same time encourage employment where possible?
4:30 p.m.	Day's Closing

Day Two: Friday, January 26

7:45 a.m.	Caregivers' Breakfast: Perspectives, Feelings and Networking (Melville Room A, Explorer Hotel)
9:00 a.m.	Welcome and Announcements
9:15 a.m.	Panel on Education: Equal Opportunities for Lifelong Learning Panelists include: Ellie Elliott, Director, School Services, Education, Culture and Employment, on recent NWT Student Support Needs Assessment; Patricia Davison, Early Childhood Intervention, Inuvialuit Regional Corporation; Liz Baille, Special Needs Consultant with

Yellowknife Catholic Schools; Parent Linda Henry on transitions to independence; MaryAnne Duchesne of the National Educational Association of Disabled Students.	
Health Break and Networking	10:00 a.m.
Small Group Discussion: How can children and adults with disabilities get the support they need to reach their potential within the NWT education system?	10:30 a.m.
Lunch Guest speaker: Kyle Prettyshield of the National Aboriginal Clearing/Connecting House on Disability Issues.	12:00 p.m.
Panel on Disability Supports: The services and equipment which people impacted by disability need and which address personal independence, participation and quality of life. Panelists include: Lani Cooke, Yellowknife Association for Community Living and Kate Tymstra, of the YWCA of Yellowknife, on supported independent living; Pat Strus, on parenting children with disabilities, including learning disabilities; Karen Laing, Human Resources, DIAND, on employment supports; Nancy Desjarlais with a first-hand perspective on psychiatric services; Cecily Hewitt, GNWT Department of Health and Social Services.	1:15 p.m.
Health Break and Networking	2:15 p.m.

2:45 p.m.	Small Group Discussion: How can people in NWT communities get the services and supports that they need?
4:00 p.m.	Day's Closing
6:30 p.m.	Dinner and Entertainment: Ethel Blondin-Andrew, Secretary of State for Children and Youth Tracy Riley Band

Day Three: Saturday, January 27

9:00 a.m.	Review of Results from Small Group Sessions: Conference participants
10:00 a.m.	Health Break and Networking
10:30 a.m.	How Can I Be Counted In?: Mary Beth Levan
11:50 a.m.	Closing Remarks: Bill Burles Closing Prayer

(Conference is expected to conclude by 12:00 p.m.)

Appendix B:
Delegate Conference Summary

Money and Dignity

A Story

"My partner does all the housework and cooking and everything. When my partner went fishing on the lake they deducted his income for those months off my disability cheque. We don't have enough money and I don't know where to get more or who to ask for help."

The Problems

- our income is far too low and means we go without basic things like food, clothing and shelter... real independent living is impossible
- our income does not allow us to pay for special equipment
- we are confused and frustrated by all the different income programs and all the red tape that goes with them
- sometimes we are treated like we are crooks, like we are trying to cheat... when all we want is to survive and live like others... and income support programs punish you if you earn money
- the income support systems are not flexible towards each person and each family... we are all just fitted onto a chart

The Solutions

- there must be higher income support levels for people with disabilities, and money for special equipment and renovations

- there must be more information about all the income support programs available, and, in the end, people with disabilities should have their own seperate pension plan like seniors
- we need to lobby for a different tax credit system, a ministerial Advisory Council, coordinated government programs, centralized and inclusive services, public awareness, bimonthly payment programs, respite and home care, an ombudsman office and training for people who work in income support programs... so we are treated with respect, and they understand our needs and strengths

Lifelong Learning for Everyone

A Story

"My child is going to kindergarten this year and he has some learning and behaviour problems. The school says I should go to Social Services, and Social Services say I should go to the Board of Education. Everyone keeps sending me back and forth... no one wants to talk about my son's needs."

The Problems

- there are not enough specialized programs and special needs teachers... there are not enough adult literacy and training programs
- many parents and teachers don't know about learning disabilities, and the special needs of all children and adults with disabilities
- it's hard to get appointments, assessments and special learning aids... there is no follow-up and you are left all alone

- children and adults with disabilities are 'managed', not educated
- children and adults with disabilities end up feeling a lot of shame

The Solutions

- we need access in all communities to the full range of assessment and remedial services (OT, PT, Speech Pathologist, psychological, etc.)
- we need to educate parents, teachers, medical people, social workers, administrators, and community people about all disabilities
- all services have to work together and follow the child through all grades into adulthood, they need coordinated planning for everyone
- we need a wide variety of alternate program options for children and adults: distance education, adult literacy, individualized programs, life skills, summer courses, tutoring, peer learning, specialized classes, learning equipment, traditional and land-based programs, mentoring programs... and the right to set our own learning goals

Services and Supports

A Story

"There are a lot of people in my community who would help us with home care and respite care if they knew what to do. As it is, they are afraid of making a mistake or doing it wrong so they are too shy to offer help. We want to keep our daughter at home but we need more help."

The Problems

- services are scattered, inconsistent and hard to access
- each level of government, and land claims organizations, say its not their responsibility
- there are more services and programs in big towns and few in small towns... families are split up... helpers come to town for short times
- our communities and the governments are not aware of the problems we face

The Solutions

- train more paraprofessionals and community people so they can offer home care and respite in connection with medical programs
- legislate services for the disabled and create a Bill of Rights for Persons with Disabilities with a Minister Responsible for Persons with Disabilities... take these services out of Income Support and establish long-term ongoing funding for all programs
- create the following services: a centralized data bank of persons with disabilities, a newsletter about, by and for persons with disabilities, inter-agency groups in all towns, travelling assessment teams, CHRs with more time for the disabled, learning aids funding, transportation systems in all towns, Junior Olympics, community buddy systems, regional and centralized conferences once a year... and using existing helpers and resources more effectively
- **We have to get assertive and make our voice heard!**

Letter to the Premier

Premier Steven Kakfwi
Government of the Northwest Territories
Yellowknife, NT

January 27, 2001

Dear Mr. Kakfwi:

This week I have attended the "Count Me In" Conference held in Yellowknife. This conference was hosted by the NWT Council for Disabled Persons and was attended by more than 160 persons impacted by disability. There were participants from almost every community in the Northwest Territories.

We discussed a lot of topics that relate to our personal experiences of living with disabilities. Enclosed is a workshop summary that outlines, in broad terms, the problems we are encountering. It also lists the solutions we will work towards in partnership with all levels of government, and with every community agency. (A full report of the conference proceedings will be forwarded to you.)

We know that solutions can be found to the many problems we are facing. We all need to work together to relieve the stress, loneliness, shame and frustration so many of us experience each day.

We are sending copies of this letter to each level of government and to all those boards, agencies and organizations with a mandate to assist, and work with persons with disabilities and their families.

I look forward to hearing from you, and to working with your government, and others, on positive and progressive initiatives for persons with disabilities.

Sincerely,

Notes

"This conference is
a foot in the door
for all
disabled persons!"

Human Resources Development Canada
Développement des ressources humaines Canada